

Comparative Effectiveness Research Review Disposition of Comments Report

Research Review Title: Closing the Quality Gap Series: Revisiting the State of the Science. Quality Improvement Measurement of Outcomes for People With Disabilities

Draft review available for public comment from January 7, 2012 to February 7, 2012.

Research Review Citation: Butler M, Kane RL, Larson S, Jeffery MM, Grove M. Closing the Quality Gap Series: Revisiting the State of the Science. Quality Improvement Measurement of Outcomes for People With Disabilities. Evidence Report 208 Part 7. (Prepared by the Minnesota Evidence-based Practice Center under Contract No. 290-2007-10064 I.) AHRQ Publication No. 12(13)-E013-EF. Rockville, MD: Agency for Healthcare Research and Quality; October 2012. Available at: www.effectivehealthcare.ahrq.gov/reports/final.cfm.

Comments to Research Review

The Effective Health Care (EHC) Program encourages the public to participate in the development of its research projects. Each comparative effectiveness research review is posted to the EHC Program Web site in draft form for public comment for a 4-week period. Comments can be submitted via the EHC Program Web site, mail or email. At the conclusion of the public comment period, authors use the commentators' submissions and comments to revise the draft comparative effectiveness research review.

Comments on draft reviews and the authors' responses to the comments are posted for public viewing on the EHC Program Web site approximately 3 months after the final research review is published. Comments are not edited for spelling, grammar, or other content errors. Each comment is listed with the name and affiliation of the commentator, if this information is provided. Commentators are not required to provide their names or affiliations in order to submit suggestions or comments.

The tables below include the responses by the authors of the review to each comment that was submitted for this draft review. The responses to comments in this disposition report are those of the authors, who are responsible for its contents, and do not necessarily represent the views of the Agency for Healthcare Research and Quality.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	General	The report is important and very broad in its scope. The target population and key questions are clear.	Thank you for the comment.
Peer Reviewer #1	General	Clarity and Usability: I think the paper needs more work to develop the recommendations more clearly. The executive summary is too long and descriptive and primarily should present the recommendations from the paper that are not yet really developed.	The discussion section has been revised.
Peer Reviewer #2	General	The article address an exceptionally important topic; i.e. measures that can be used to quantify quality of health outcomes of people with disabilities. The topic is especially relevant since PWD are known to be "high end" health care users while having less than optimal health outcomes. Review of the state of science in this area helps to inform future research. Key questions are clearly articulated and justified.	Thank you for the comment.
Peer Reviewer #2	General	Clarity and Usability: The report is very well-written, organized, and understandable. The conclusions can be used to inform the field of tool development relative to disability outcomes.	Thank you for the comment.
Peer Reviewer #3	General	The report is clinically meaningful in the sense that it illustrates both gaps in measure testing with disabled population and potential gaps in the way clinicians may approach treatment of their patients with disabilities. The key questions are relevant and explicitly stated. However, as the authors note, the literature search to address the key question was not sufficiently exhaustive nor strategic to be considered more than a "sample." Therefore it is a little difficult to say whether the key questions have been answered or the conclusions drawn by the authors fully-supported.	Thank you for the comment. The search was conducted systematically and extensively. However, given the current processes for indexing publications, it is very challenging to develop sensitive search algorithms with enough specificity for reasonable screening and resource use for broad outcome topics. Within the systematic review field, when a body of literature is diffuse and hard to identify, it is reasonable to infer that the field of inquiry is relatively nascent and unformed.
Peer Reviewer #3	General	in addition, it is not entirely clear who the intended audience for this research is. The detailed and comprehensive introduction lays out nicely the paradigms for viewing disability and should serve as an excellent overview for readers who do not work in disability research. However the conclusions and next steps are more appropriate for researchers already familiar with these populations and frameworks.	The intended audience has been stated more clearly.
Peer Reviewer #3	General	Clarity and Usability: The report is well-structured and clearly organized. The introductory material is informative and the documentation of findings concise. However, as noted above the implications for future research and policy could be more explicitly articulated.	Thank you for the comment.

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Peer Reviewer #4	General	This is one of the most seminal, thought provoking and beautifully balanced I have ever reviewed! I believe it can be truly transformational.	Thank you for the comment.
Peer Reviewer #4	General	There are a number of important overall points made for policy makers, researchers and clinicians- examples include 1. The importance of maintaining function in working age people (critical to policy improvement). 2- Conceptual problems with DALYs (critical to researchers as well as policy makers in avoiding assumptions that could be damaging to and increase disparities experienced by people with disabilities). 3- Expanded models of disability and need for care linkages across sectors (Important to clinicians, researchers and policy makers). 4- Usual conditions manifest differently in people with disabilities (important to clinicians).	Thank you for the comment.
Peer Reviewer #4	General	The focus on health care outcomes for general medical care with respect to people with disabilities is an important area particularly as it relates to care coordination and quality improvement.	Thank you for the comment.
Peer Reviewer #4	General	The overall "context of disability as a comorbidity" is confusing. In medicine, comorbidity tends to imply chronic medical illnesses as well as the synergistic or multiplicative impacts of such conditions, rather than function. As you imply in the review of various models, disability is a differing construct typically the combined result of single or multiple injuries and diagnoses. Because disability is caused by comorbid medical conditions (the end result of comorbidity) it is misleading and circular to characterize disability as a comorbidity. You might talk about disability as a complicating condition or manifestation of comorbidity. If a comorbidity causes a disability it is more severe. Alternatively you might reframe the comorbidity concept as being broader to include comorbid diagnoses as well as comorbid activity limitations and participation restrictions. I still would find this a little confusing.	We have adjusted the language throughout the report, replacing "comorbidity" with "complicating factor" or other similar language to address the potential to confuse the readers. We also directly addressed in the Disability Paradigms section the different taxonomies of "comorbidity" vs "complicating condition" as an example of the challenges in communicating across medical, rehabilitation, and social service fields.
Peer Reviewer #4	General	The magnitude of review and its summary is impressive.	Thank you for the comment.
Peer Reviewer #4	General	Clarity and Usability: Yes. I would suggest moving some materials that appear in the introduction into the discussion. The former is long and latter short.	We have expanded the discussion.

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Peer Reviewer #5	General	I believe that the monograph is clinically meaningful in that it introduces important distinctions between the accepted measures of health quality among non-disabled individuals and those that may be more directly relevant to the health care outcomes of individuals who also have a disability. It is hoped that by expanding research into more outcome measures for this population that clinical practice will also be improved.	Thank you for the comment.
Peer Reviewer #5	General	I believe that the key questions are clearly stated.	Thank you for the comment.
Peer Reviewer #5	General	I think that the audiences could be more clearly stated – including public managers, managed care entities, etc.	The audience was more clearly stated in the introduction.
Peer Reviewer #5	General	Clarity and Usability: This is a small point, but the executive summary seemed almost as long as the article itself. It made the longer discussion fairly redundant. Are you expecting that the summary and the full article are for two different audiences? Otherwise, I think that the executive summary could be shortened. Also, as I mentioned above, it would be great to put the need for these indicators and measures in a practical context.	Within the EPC program, Executive Summaries are viewed as stand-alone documents similar to journal articles. We revised and edited the Executive Summary to respond to reviewer comments and for clarity. However, we did not significantly reduce its length.
Peer Reviewer #6	General	This report begins with an excellent conceptual framework for considering outcome measurement issues as they relate to research and quality improvement for people with disabilities including levels of analysis (public policy, impact of organized programs, and whether interventions target the disability, the medical condition, the broader service system, or an integration of these); the medical, social, and biopsychosocial models of disability; the medical, rehabilitation, social, discipline, and consumer perspectives; and the potential outcome domains contained in the ICF and the ones not included in the ICF. These multiple broad conceptual frameworks then abruptly lead to specific key questions to be addressed by the report, but there could have been so many more and the rationale for the limited set of questions is unclear. These key questions are then further limited by a set of inclusion and exclusion criteria which, while seeming reasonable for practical reasons, are not well justified. Were these restrictions included in the charge to the group authoring the report or were they self-imposed?	Thank you for the comments. The inclusion/exclusion criteria were self-imposed, with input from the technical expert panel, largely for practical reasons. There potential sample of articles that would be identified by search algorithms had to be reduced to a feasible set. As stated in the report, it is very difficult to write search algorithms that are specific to the topic, and bounds had to be created.
Peer Reviewer #6	General	In general the report does what it said it would do, listing outcome measures meeting prescribed criteria used for research and quality improvement among people with disabilities, but little synthesis and interpretation of the findings was provided, leading to few specific recommendations for further research.	We have expanded the research recommendations.

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Peer Reviewer #7	General	Terminology is idiosyncratic. I disagree with a main point: it is not useful to consider disability as a comorbidity. Disability is different from morbidity, as the ICF and Nagi frameworks have consistently distinguished. Perhaps that explains “We found very few direct examples of work conducted from the perspective of disability as comorbidity.” Can this be just be a bit more simple and talk about whether disability makes a difference in outcomes?	We acknowledge the varying perspectives and, as noted above, now use the term “complicating condition.”
Peer Reviewer #7	General	Clarity and Usability: No. This needs to be written more accessibly. There is far too much prefatory material about definitions, levels of analysis (or different types of interventions actually), classification schemes. The authors also lose track of the specific terminology that has been developed, such as people with disabilities vs. disabled persons. I think the basic question to be answered is how clinically different are people with disabilities from the general population and how that presents challenges to health care delivery and QI.	We have tried to note the variety of perspectives. Not everyone views the issue as directly as this.
Public Comment #1 AAPM&R	General	The Academy strongly supports the investment of time and resources by AHRQ into studying issues related to healthcare for people with disabilities into the rubric of performance measures. We applaud the effort to recognize that this community shouldn't fall into the category of exceptions to the quality improvement landscape.	Thank you for the comment.
Public Comment #1 AAPM&R	General	The Academy supports the findings of this study and strongly recommends that any future research addressing the needs of people with disabilities focus on the coordination of care in disability research utilizing the framework of measures to include: patient experience; family experience; family caregiving burden; provide experience; functional status, independence, and community participation; health status, prevention of secondary conditions; fidelity to the care coordination process; and access to care measures.	Thank you for the comment, and support of the future research recommendation for suggested care coordination outcomes.
Public Comment #1 AOTA	General	We are pleased to see this report which clearly identifies research gaps, such as the paucity of studies examining disability as comorbidity.	Thank you for the comment.
Public Comment #4 Rebecca Trocki	Abstract	For the sentence, We looked at generic outcomes measures rather than the disability-specific measures, and for examples of outcomes used in the context of disability as a comorbidity for a set of set of basic service needs and secondary conditions common to disability problems. This is very long sentence and need clarification. Can you explain the limitations of the study. Either the sentence can be simpler or better stated with the abstract to fully understand the paper.	The sentence in the abstract was clarified.

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Peer Reviewer #1	Executive Summary	The abstract was well written but I thought the executive summary was entirely too long. By the time I finished reading it, I was not sure what the report would add. I would cut the executive summary down from 17 pages to no more than 4-5 pages and take out most of the background on the definitions and all the tables and graphs. The most important section has the recommendations and these were too general to develop actions. I think the executive summary and recommendations need to be written more like the format used in IOM reports.	Within the EPC program, Executive Summaries are viewed as stand-alone documents similar to journal articles. We revised and edited the Executive Summary to respond to reviewer comments and for clarity. However, we did not significantly reduce its length.
Peer Reviewer #3	Executive Summary	The Executive Summary should include the justification for why serious mental illness was excluded. Similarly, the list of countries included in the search criteria also should be explained in the Executive Summary. The rationale for both in the main report is clear and defensible, but excluding it from the ES raises questions.	The suggestion was adopted.
Public Comment #2 AOTA	Executive Summary	In Table ES-1 (p. ES-2), the third row identifying „Specific interventions directed at the disability” refers to Common Questions such as “Changes in function, Quality of Life”. Although this is probably not meant to be an exhaustive list, AOTA respectfully suggests further explication under “Common Questions”. In lieu of “Changes in function, and Quality of Life”, we suggest adding “Changes in Body Structure and Function , Changes in Activities (routine), Changes in Participation ”. We think that including levels of ICF framework in this table would help facilitate analysis of the levels at which interventions are directed. We may find that a majority of intervention research are directed at the body structure and function level, but people with disabilities may be concerned with their ability and satisfaction of performing daily activities and participating in their community events. As this report notes in a discussion about the individual’s perspective, focus groups revealed that people with disabilities are concerned about: “the ability to function and the opportunity to do what you want, independence and self-determination, an interrelated physical and emotional state of well-being, and being unencumbered by pain” (p.9).	The suggestion was adopted.
Public Comment #2 AOTA	Executive Summary	Within the last row of Table ES-1 (p. ES-2), “Comprehensive programs designed to integrate medical and social services”, does research aimed at preventing secondary conditions or negative events like falls/accidents fall within this category? AOTA advocates for preventing secondary conditions and negative events because research has shown that they can adversely affect one’s health and quality of life.	The suggestion was adopted.

Commentator & Affiliation	Section	Comment	Response
Public Comment #3 APTA	Executive Summary	APTA has concerns about the adapted ICF framework as presented in this draft report. The adapted ICF framework indicates that the relationships are linear, where in the ICF, they are not. Any intervention provided that focuses on any of the components, the health condition, body structures and function, activity, participation, environment and personal factors, can interact with or have an impact on the other components within the framework resulting in function or disability. The process is not linear as rehabilitation interventions can occur at any point within any component. The inclusion of figure ES-3 and its associated explanation is not an accurate representation of practice or the ICF framework, and APTA recommends that it be removed from this draft report.	The linear framework was easier to understand by other reviewers, so it was left in. We highlighted that the linear framework is a simplified version and may differ by situation in order to address the reviewer's concerns.
Peer Reviewer #7	Executive Summary	The Executive Summary is far too detailed, too long, and very difficult to read with any sustained interest.	We have revised the executive summary but it is still long. See comments above.
Peer Reviewer #1	Introduction	The introduction is well written and the framework is very nicely developed although it is very long. The key questions are not addressed until p. 14. It is not clear how the framework is used in the methodology. Perhaps some of the background material in the introduction (such as the outcome measures in research on p 11) could be moved to the discussion section which seems too limited for such as extensive review.	We clarified the framework used for the key questions. The introduction was left in its extended form because other reviewers/commenters less familiar with the topic observed that exposure to the material before the results was helpful to the reader with understanding and interpreting the results and discussion.
Peer Reviewer #2	Introduction	On page 3, line 21, the authors indicate that the social model generally frames the disabling condition, rather than the person, as the problem. I would interpret the social model as framing the problem as the societal response to disabling conditions. The authors go on to support this notion in the subsequent text. I suggest rewording this sentence.	The suggestion was adopted.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #2	Introduction	On page 8, line 32 (and in other sections of the text) I found the notion of disability as a comorbid condition confusing. It is my understanding from the authors explanation of this concept that they are referring to disability as an independent risk factor for outcomes of interest in addition to comorbid conditions. Describing disability, which is an interactive, multi-dimensional, and dynamic concept, as a health condition, over-simplifies how we conceptualize its contribution to predicting important outcomes. It is confusing to refer to disability in the disease sense along side other conditions like arthritis or heart disease. If this is not what the authors intended to convey, then the notion of disability as a comorbid condition needs to be more fully developed in the introduction. Similarly, on page 11, line 53, disability may not be a confounder, it may be in the causal pathway which would warrant different analytical approaches. In my opinion, this is the one area that requires considerable clarification in the report which is otherwise extremely clear and well-written.	We have adjusted the language throughout the report, replacing “comorbidity” with “complicating factor” or other similar language to address the potential to confuse the readers. We also directly addressed in the Disability Paradigms section the different taxonomies of “comorbidity” vs “complicating condition” as an example of the challenges in communicating across medical, rehabilitation, and social service fields.
Peer Reviewer #2	Introduction	On page 13, lines 5-6, body structure/function is not measured at the whole person level. The ICF clarifies that body structures are organs, limbs, and their components classified according to body systems. Body functions are physiological functions of body systems. Referring to the Nagi model from which these terms originated, impairment is measured at the organ or organ system level. Impairment is the negative aspect of body functions and structures. It reflects a loss or abnormality (dysfunction) in body structure, physiological function, or biochemical function, including mental and emotional functions. Examples are decreased strength or poor balance. Impairments may or may not affect whole person functioning which is measured at the activity and participation level. This needs to be clarified in the report when referring to “level 2” of the ICF.	Thank you for the comment. The illustration and discussion is taken directly from WHO sources; the reviewer’s comments are well-taken as yet another example of the complexity of conceptualizing disability and the difficulty of creating adequate pictures to convey the complexity. Since there was not a unanimous view by reviewers on the report’s ICF discussion, we viewed the discussion as adequate for the purposes of this report and left it unchanged.
Peer Reviewer #3	Introduction	The various frameworks presented are helpful and clearly explained, but the lifecycle models seem a little simplistic and/or rigid. The authors seem to imply that people with disabilities fall neatly into one category or another. Social integration may remain a top priority for elders – living life to the fullest rather than trying to arrest decline. If this was not the intent (and I suspect it was not) the fluidity of these models should be emphasized more.	We emphasized on page 1 the conceptual nature of the frameworks and encouraged readers to not view the different categories, classes, or paradigms as mutually exclusive or clear distinctions with clean boundaries.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Introduction	Different models of viewing and defining disability are clear and are a useful introduction for the non-subject matter expert. However, again the asserted alignment between disability paradigms and various professions seems too rigid and simplistic (and perhaps judgmental?). The overlaps in the Venn diagram do speak to the fact that the paradigms need not be mutually-exclusive.	We emphasized on page 1 the conceptual nature of the frameworks and encouraged readers to not view the different categories, classes, or paradigms as mutually exclusive or clear distinctions with clean boundaries.
Peer Reviewer #3	Introduction	The authors note "Table 2 illustrates some relevant outcomes. Those for developmental and acquired disability are virtually the same; both emphasize societal integration. In contrast, those for aging emphasize more limited functional goals, and indirect effects on costs and utilization of additional services." It is not clear what criteria were used to deem the outcomes in Table 2 "relevant" and again the distinction between the populations seems a bit artificial and forced.	We emphasized on page 1 the conceptual nature of the frameworks and encouraged readers to not view the different categories, classes, or paradigms as mutually exclusive or clear distinctions with clean boundaries.
Peer Reviewer #3	Introduction	Figure ES-1/Figure 2 is misleading; although the disclaimer notes an effort to show relative values only, the use of pie charts implies actual data. Further these charts were hard to interpret in term of the directionality (read down or across?). Vignettes illustrating how a specific individuals needs change over time would probably make the point better.	We have revised the figure for easier interpretation.
Peer Reviewer #3	Introduction	Figure ES-3/Figure 4 is than ES-2/Figure 3 in illustrating the model, but neither is intuitive. Would suggest including only one.	Figure ES-3/Figure 4 is more intuitive for interventionists who tend toward a linear view. Figure ES-2/Figure 3 is WHO's illustration of the ICF as they developed it. Both speak to different audiences.
Peer Reviewer #4	Introduction	Well framed concise and clear	Thank you for the comment.
Peer Reviewer #4	Introduction	Clearly links report to the 2003 IOM report "Priority Areas for National Action". Well motivated by AHRQ's identification of people with disabilities as a priority population.	Thank you for the comment.
Peer Reviewer #4	Introduction	Appropriately sets up a broad framework recognizing that disability management requires care coordination across multiple sectors.	Thank you for the comment.
Peer Reviewer #4	Introduction	Emphasizes that function, quality of life and community integration are interdependent and that coordination often needs to span the spectrums of both care and support services (e.g. medical care and social services).	Thank you for the comment.
Peer Reviewer #4	Introduction	Table 1: Levels of analysis for research provides a clear framework.	Thank you for the comment.

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Peer Reviewer #4	Introduction	In your discussions you note that disability exerts a direct effect on the outcome, in addition to the effect of disease.” This description is consistent with our findings, and is supported empirically by a multivariate analysis of more than 2,000 veterans who underwent rehabilitation after amputation of the leg(s). We demonstrated that both medical comorbidity and disability had direct effects on mortality. Medical comorbidities also influenced mortality indirectly through its impact on disability and also through its effect on activity limitation (ICF label), acting as a mediator (see figure 1 in the paper). Stineman MG, Kurichi JE, Kwong PL, Maislin G, Reker DM, Vogel WB, Prvu-Bettger JA, Bidelsbach DE, Bates BE: Survival analysis in amputees based on physical independence grade achievement. Arch Surg 144(6):543-51, 2009. (PMC2869628)	Thank you for the comment. We have added the reference.
Peer Reviewer #4	Introduction	Acknowledges need for disability-appropriate outcome measures.	Thank you for the comment.
Peer Reviewer #4	Introduction	Use of imbedded questions effectively engages the reader and draws attention to the technical materials in the body of the report.	Thank you for the comment.
Peer Reviewer #4	Introduction	Many times when the term “Disability” is used it would be more precise to state whether impairment or activity limitation is being discussed.	We changed the terms to impairment or activity limitation where the distinction between impairment and activity limitation could be made. Where either impairment or activity limitation could be implied, we used the more general term of disability.
Peer Reviewer #4	Introduction	Clear and appropriate recognition that model selection should depend on purpose. Clearly described the biomedical, and biopsychosocial models and distinctions between them with respect to how disability is viewed by these models. In discussing the medical model, social model and biopsychosocial models consider greater emphasis on how the social model in general leads to a broadening of the medical model towards consideration of social and cultural factors. The social model relates more to social advocacy agenda than to medicine although it can be considered a legitimate model of disability as a concept that has both medical and societal implications. Its inclusion is essential and feeds back to one of your key concepts i.e. management of disability must span medical and social services.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Introduction	It is forward looking to acknowledge the ongoing need to understand the complexities of disability-related research. Your inclusion of the biopsychosocial model as one example of an integrative and comprehensive conceptual model that acknowledges and works with the complexity of disability-related research and provides the full healthcare spectrum is exciting. Your description is thoughtful and accurate. With regard to the statement, "Which incorporates theories of HEI" this can be referenced by the following presentation of that theory: Stineman MG: A model of health environmental integration. Top Stroke Rehabil 8(2):34-45, 2001.	Thank you for the comment. The reference was added.
Peer Reviewer #4	Introduction	The Rehabilitation Paradigm: When describing rehabilitation, please consider changing your language from –restoring level of function from “normal” or to “the level of function they enjoyed prior to the disability” to something like- Rehabilitation is intended to maximize function and optimize potential opportunities to participate in life as desired by the individual”. The concept of “normal” reinforces the “cure”, similarly the language, “the level of function they enjoyed prior to the disabilities”, is an objective which is typically impossible and is not consistent with what we try to do in rehab! Many people must live out the rest of their lives with residual activity limitation and participation restriction (as you acknowledge later). The key is to empower them to live optimally even when cure and “normal” function are not possible. You make this point clearly in the main report but it needs to be emphasized more in the executive summary. A key point about rehab is it is the single medical profession which is not primarily cure focused. We work with people who other specialties of medicine can no longer help i.e. they cannot cure.	The suggestion was adopted.
Peer Reviewer #4	Introduction	Consider adding a fourth sphere to figure 1- Labeled, “Environment (Independent Living)”. If you decide to take this direction, you can then develop a paragraph in the spirit of your Medical focused Rehabilitation paradigms and Social paradigms labeled, Independent living paradigm”. This paradigm emphasizes return of people to independent living and engagement in their larger community environments. Independent living programs IL can be described here. This leads back to the medical, the biopsychosocial, and the biopsychosocial models, the latter which is now being cited as a model within rehabilitation Medicine as important because it takes into account the “full range of human experience in the world.” Quote is from the following reference: Kirschner KL, Breslin ML, Iezzoni LI et al. Attending to inclusion: people with disabilities and health-care reform. PM R 2009; 1: 957-963	Thank you for the suggestion. We integrated Independent Living paradigm into the current framework by suggesting that it could be viewed as overlaying the 3 professional paradigms.

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Peer Reviewer #4	Introduction	Figure 2: Provides a nice sense of how there is a need to mix and match service types to meet the need of individuals depending on the nature of disabilities, thus informing the discussion of different conceptual etiologies that follows.	Thank you for the comment.
Peer Reviewer #4	Introduction	Similarly Table 2: Illustrates how different outcomes are appropriate for differing disability types. The tendency of medical professionals to be distracted by and focus on disability rather than on the person and his or her need for basic medical care for the management of generic issues such as blood pressure management is an essential. As a clinician I have seen people with serious disabilities whose critical symptoms (such as difficulty breathing) have been overlooked because physicians who do not know them are distracted by the stable manifestations of their disabilities, such as severe joint contractures. It will be important to monitor the impact of changing trends in care. The hospitalist trend, as example, where patients are admitted to hospitals under the care of hospital specialized physicians who do not know them is particularly worrisome for people with disabilities. The manifestations of the disability can cause their care to fall outside recommendations made by typical evidence based guideline recommendations often applied in such settings.	Thank you for the comment.
Peer Reviewer #4	Introduction	Table 2 provides examples of outcome by major disability etiology. The column labeled "Disability type" i.e. Developmental, acquired and aging would be more accurately labeled as "timing of onset".	The column header has been modified.
Peer Reviewer #4	Introduction	Similarly, in your text it is noted that disabilities can be characterized as physical, intellectual or developmental. Physical and intellectual are a general type. Please consider adding sensory (blindness/deafness) to that list, making it consistent with the National Healthcare Disparities Report by AHRQ cited below-"Physical, sensory and/or mental health". Developmental works better in your second list (where you also have it). This later list which rather than etiology is more related to timing of disability onset within the life cycle. Finally the comparison of trauma versus manifestations of illness relate to different etiologies.	We have added sensory to the general types list, and removed developmental, so it remains only on the second list of etiology/onset. We also adjusted the wording to refine the clarity of general type vs etiology/onset.

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Peer Reviewer #4	Introduction	I had some concern about the catheter illustration. Although it addresses an important point it also undermines an important medical goal i.e. avoiding urinary catheterization if at all possible. If this example is used please provide some type of caveat or explanation... i.e. the current clinical wisdom is to avoid catheter use if at all possible since this foreign body in the bladder enhances risk of bacterial colonization and infection. You might expand this discussion illustrating that patient preference can (at times) conflict with concepts of best practices i.e. clinical judgment.	We have added the caveat in the form of preferences vs clinical judgment.
Peer Reviewer #4	Introduction	Table 3: Appears contradictory- See the following row: #4. Chronic conditions with normal function and living with illness or disability. Generally we do not have disability in the setting of normal function- although I see the tabular material appears to be from a published reference.	The material in question in row #4 is a direct replication of the published table. We have left it unchanged.
Peer Reviewer #4	Introduction	Again distinction between medical, rehab and supportive care and coordination across these phases is an important emphasis.	Thank you for the comment.
Peer Reviewer #4	Introduction	The “aging into” and “Aging with” perspectives <i>Life course perspective</i> Distinctions between outcomes shared with general populations and how they may require modification for people with disabilities is an important point of emphasis.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Introduction	<p>Individual's perspective and Relevant Outcome Domains You note that it is essential to look at how people with disabilities and those who care for them see disability. Your discussions drawing distinctions between generic versus disability-specific measurement is important. This is a little different from the question of individual versus population-level perspectives. Your statements about individual measurement might be informed by recovery choice pathways where people are asked to select an optimal pattern of functional recovery. Work on recovery choice pathways suggest individual patients with disabilities (See Kurz et. Al.) and particularly patients with disabilities when compared to the clinicians who care for them see the implication of alternative types of activity limitation and the importance of recovery quite differently (Stineman). Even rehabilitation professionals with different training perspectives i.e. MDs, nurses, PTs, OTs (see Rist et al.) tend to show subtle differences in values (See Rist), as do those from cultures, nations or environments (See Ditunno). These differences have implications for measurement, goal setting and how we chose to scale measures when addressing HRQOL. Yet as you acknowledge when doing population surveillance we need to measure in a standard way drawing inferences that are distinct from the individual's perspective. Disability staging, by providing thresholds of function specifying the specific activities people are still able to perform is an emerging technology that can identify homogeneous groups of individual people while still providing specific information more relevant to understanding individual need.</p> <p>Ditunno PL, Patrick M, Stineman M, Morganti B, Townson AF, Ditunno JF: Cross-cultural differences in preference for recovery of mobility among spinal cord injury rehabilitation professionals. Spinal Cord 44(9):567-575, 2006. Kurz AE, Saint-Louis N, Burke JP, Stineman MG: Exploring the personal reality of disability and recovery: A tool for empowering the rehabilitation process. Qualitative Health Researc 18(1)90-105, 2008. (PMC2879973) Stineman MG, Rist PM, Kurichi JE, Maislin G: Disability meanings according to patients andclinicians: Imagined recovery choice pathways. Qual Life Res 18:389-398, 2009.(PMC2862634) Rist PM, Fries DW, Maislin G, Stineman MG: Recovery from disablement: What functional abilities do rehabilitation professionals value the most? Arch Phys Med Rehabil 89(8):1600-1606, 2008. (PMC2884270)</p>	We have included statements on disability staging as possible. The recovery choice pathways appears to address disability treatment, which is outside the scope of this review.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Introduction	You make an essential point i.e. that DALY and QALY constructs place an immediate ceiling on the potential benefit people with disabilities can achieve because their baseline status downgrades the QALY score. You go on to say that using such measures in making policy decisions thus has substantial implications for people with disabilities. I applaud you for that statement. Although QALYs and DALYs represent improvement over mortality as an end point when comparing the benefits of alternative treatments or implications of reducing injury (see Spicer), use of QALYs and DALYs in policy decisions particularly if they relate to determining who gets what type of care when is dangerous and potentially discriminatory. However, some might still argue the validity of using weightings based on population determined values rather than the values of those with the disabilities in question as you noted above. Spicer RS, Miller TR, Hendrie D, Blincoe LJ. Quality-adjusted life years lost to road crash injury: updating the injury impairment index. <i>Ann Adv Automot Med</i> .55:365-377.	Thank you for the comment. The reference was added.
Peer Reviewer #4	Introduction	Your notes on the exclusion of people with disabilities from research due to lack of access is very sensitively written.	Thank you for the comment.
Peer Reviewer #4	Introduction	ICF as an organizing framework Nicely described.	Thank you for the comment.
Peer Reviewer #4	Introduction	You make the point that this framework does not include process measures and also needs psychometric studies. This is supported by our work where we confirmed through factor analyses that ADLs and IADLs generally fall within the distinct self care and domestic life chapter domains of the ICF but certain activities listed within those chapters did not fit. Stineman MG, Ross RN, Maislin G: Functional status measures for integrating medical and social care. <i>International Journal of Integrated Care</i> [serial online] 2005 Dec. 21;5. Available from: URL: http://www.ijic.org/ [cited 2005 Dec. 21]. (PMC1475730)	Thank you for the comment. The reference has been added.
Peer Reviewer #4	Introduction	Your definition of secondary conditions as conditions that people with disabilities are more likely to experience because of their disability is informative- Consider keeping ambulatory care sensitive conditions outside this secondary condition definition. ACSs as a quality measure for studying disparities among people with disabilities as you state is a prime target for future QI initiatives. Conditions that people with disabilities are more likely to experience may overlap with but are also distinct from ACS conditions. Including them in the same blanket definition reduces conceptual clarity. Some ACSs would also be conditions more common among those with disabilities but not all.	We have clarified the definition of included conditions to keep the two terms distinct.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Introduction	KEY QUESTIONS These are clear as is project scope. The concentration on coordination of care as a major component for potential quality improvement initiative is strategic. In my experience as a clinician this is where care breaks down particularly in transfer of patients across service lines and from institutions to the community and back again. The hospitalist model where physicians receive new patients unknown to them is particularly dangerous for people with disabilities many of whom have complex needs that invalidate simplified evidence based guideline care. A statement acknowledging the potential limitations of evidence based practice guidelines and even the potential danger applying them blindly and in a standard manner to people with particular types of disabilities might be prudent.	Thank you for the comment. We have addressed this issue by expanding the discussion of a bank of care coordination measures in the discussion section.
Peer Reviewer #4	Introduction	Care Coordination The broad approaches listed (bullet points) seem reasonable as cited to the CQG series. There are two important areas missing that might be considered 1- Enhancing patient provider communication and 2- Evidence of person-centered care.	The suggestion was adopted.
Peer Reviewer #4	Introduction	Measures Appropriate	Thank you for the comment.
Peer Reviewer #5	Introduction	I think it would be useful for the authors to put this analysis into the larger public policy context – e.g., changes in health care systems, adoption of blended Long-term care services and acute care services; the need for performance metrics for new models, etc.	We have noted the review is currently grounded in the CQG and AHRQ's responsibility to priority populations. In addition we noted the relevance of policy related to integrated care and medical homes.
Peer Reviewer #5	Introduction	I particularly liked the fact that the monograph used as a conceptual framework the 3 approaches to interventions with people with disabilities. The chart showing the ratio of different types of support based on age, etc. was particularly evocative.	Thank you for the comment.
Peer Reviewer #7	Introduction	Please, replace confined to a wheelchair with uses a wheelchair.	The language has been modified.
Public Comments #1 AAPM&R	Introduction	The Academy believes that AHRQ must recognize that disability cannot be separated from other experiences or disease processes by the patient in the same way as other co-morbidities. Moreover, definitions of co-morbidity include words like illness, disease and pathologic processes, none of which encompass the full concept of disability, making co-morbidity an inappropriate term to describe this condition. The Academy recommends that research clarify the confounding, mediating and interacting effect disability has on the outcomes of interventions and services. However, the word co-morbidity is not appropriate to describe these effects.	We have adjusted the language throughout the report, replacing "comorbidity" with "complicating factor" or other similar language to address the potential to confuse the readers. We also directly addressed in the Disability Paradigms section the different taxonomies of "comorbidity" vs "complicating condition" as an example of the challenges in communicating across medical, rehabilitation, and social service fields.

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Commentator & Affiliation	Section	Comment	Response
Public Comments #1 AAPM&R	Introduction	The use of the phrase “confined to a wheelchair” as a descriptor within the report, should be reconsidered in future public documents because of its negative connotation. More appropriate terminology which could be considered is “individuals who are wheelchair users” or “individuals who use wheelchairs for mobility”.	The language has been modified.
Public Comments #2 AOTA	Introduction	Under Disability Paradigms (p.4), we take issue with the implication that only the Social perspective supports and empowers “people who have disabilities to be full participants in their families, communities, and schools, whether or not their disability or related medical conditions can be cured or fixed”. Rehabilitation professionals also emphasize participation and healthy adaptation of clients across the lifespan and across the continuum of care. Examples of rehabilitation interventions that address participation and adaptation include: (a) ensuring safe access to all areas of one’s home and work/school, (b) providing adaptive equipment and/or mobility devices for shopping, dressing, and cooking, (c) evaluating driving ability and need for car modifications, and (d) helping people with disabilities to resume or start participating in leisure activities (e.g., adaptive skiing, sports with wheelchair users, low-vision adaptations for crafting/sewing).	Thank you for the comment. The report emphasizes that the categories, paradigms, and classifications are not hard and fast distinctions. People with disabilities, and those who provide services to them, represent complex needs and solutions. Further, language in the rehabilitation paradigm has been changed to read “This paradigm strives to maximize function and optimize potential opportunities to participate in life as desired by the individual A key point about Rehabilitation is it not cure-focused, which is not the case for most other medical professions.”
Public Comments #2 AOTA	Introduction	While the discussion about type of disability (e.g., acquired, developmental) and treatment continuum e.g., (remediation) is useful in some cases, the reality of most people with disabilities seeking treatment is not so clear cut. In most cases, people with disabilities, or who are at high-risk for a disability, seek remediation as well as compensation/adaptation. Occupational therapists working with a person who has had a stroke may be implementing a constraint-induced movement therapy protocol (i.e., remediation) as well as teaching compensatory strategies for dressing, cooking, and bathing.	Thank you for the comment.
Public Comments #2 AOTA	Introduction	We would also like to comment on the example of a disability activist on p. 8. Although this is a good example of how individuals’ priorities may differ at various times, we respectfully suggest deleting the phrases “confined to a wheelchair” and replacing the phrases so that the sentence would read, “A disability activist, who has paraplegia and uses a wheelchair, is visiting his father, who just recently became a wheelchair user because of a stroke.”	The sentence has been adopted.

Commentator & Affiliation	Section	Comment	Response
Public Comments #2 AOTA	Introduction	In the section describing Outcome Measures in Research for People with Disabilities (p.11), we agree with the bulleted list of characteristics of measurement tools that should be considered by researchers. We urgently need more research that examines the outcomes of people with disabilities at the Activity and Participation levels of the ICF. While research is still needed at the body structure and function levels of the ICF, this research should be explicitly linked to Activity and Participation because outcomes need to be meaningful to people with disabilities. As an adult with cerebral palsy stated in a discussion about the need for more research about activities of daily living, "It [ADL] is so important."	Thank you for the comment.
Public Comments #2 AOTA	Introduction	We agree with the point that ADL performance can fluctuate widely over time (p.12), due to the variability of the disease (e.g., MS), side effects of certain medications, and even environment. Occupational therapists know that the ADL performance of inpatients may differ greatly once they are home because of differences between hospital (e.g., grab bars in bathroom) and home environments (e.g., lower toilet height).	Thank you for the comment.
Public Comments #2 AOTA	Introduction	In Figure 4 (p.14), AOTA views Rehabilitation's role more broadly than the figure depicts. Please see Fig. 1 for our conceptualization of the relationships between ICF and medical and rehabilitation's roles. Occupational therapists view environments and personal factors as important variables that can affect one's abilities and performance, through motivational factors and enabling characteristics of the environment. Similarly, adaptation interventions can influence one's abilities and performance. For example, with a dressing stick and sock aid, a person with paraplegia may be able to don pants and socks independently. In client-centered practice, the treatment or prevention would promote/enable the client to live life (i.e., perform meaningful tasks) to his/her fullest extent.	The Figure has been modified to include the "cure", "restore", and "support" language to emphasize function rather than role.

Commentator & Affiliation	Section	Comment	Response
Public Comments #3 APTA	Introduction	<p>"The Rehabilitation perspective includes health care professionals such as physiatrists, physical therapists , occupational therapists, and speech therapists. Patient populations include people with temporary disability due to trauma or illness, and people with "stable" disabling conditions. This perspective strives to return the person to his/her previous level of functioning. For people with newly disabling conditions, this means restoring the level of function they enjoyed prior to the disability. Here, too, the medical and biopsychosocial models may inform providers' work. However, the biopsychosocial model, which takes into account the interaction of personal and environmental factors on functioning and the health condition, predominately informs commonly used disablement frameworks.... For people with developmental and acquired disabilities, care emphasizes habilitation and rehabilitation services. Medical care is relevant only to the extent that the individual suffers from general problems that people of that age group experience, or from specific disease complications of the underlying condition. At the same time, disabilities may present access barriers to medical care (e.g., getting onto an exam table). Medical practitioners may need special knowledge about how to treat a given disease in the context of the disability. Successful care is generally measured using outcomes related to functioning and societal integration."</p>	Modifications to the Rehabilitation perspective paragraph have been made.
Public Comments #3 APTA	Introduction	<p>APTA suggests that the use of the World Health Organization Disability Assessment Schedule II (WHODASII) may be helpful in obtaining cost and utilization information to examine second order services. The WHODASII can be used to "identify needs, match patients to interventions, track functioning over time, and measure clinical outcomes and treatment effectiveness".</p>	A sentence has been added to the section, suggesting the use of the WHODAS 2 to aggregate information on utilization.
Public Comments #3 APTA	Introduction	<p>APTA applauds the inclusion of medical conditions and secondary conditions common across populations of community-dwelling disabled individuals that are included in the scope of this draft report. However, we feel that Alzheimer's, osteoarthritis, and osteoporosis (including falls) should also be included in this report, since these conditions have an impact on both the process and the patient centered outcomes.</p>	The conditions mentioned, along with a number of others, can and do impact process and outcomes. However, given the current definitions of basic service needs and secondary conditions that overlap ambulatory care-sensitive conditions, they are outside the scope of this review.
Public Comments #3 APTA	Introduction	<p>Additionally, although APTA recognizes the issues with including condition specific measures in the scope of this work, we do feel that they would be informative in measuring outcomes.</p>	See above.

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Peer Reviewer #1	Methods	The methods and criteria used in the review seem fine but the link between the methods and the framework of the study is not clear. How was the review linked to the major paradigms and perspectives as well as to the ICF framework? It might have been better just to focus on either the basic medical services or care coordination in the review between there were so many articles for both areas.	The project scope section has been modified to clarify that the linkage to the ICF was held to the higher level of the ICF system. Detailed mapping to specific coding provided in the ICF chapters was outside the scope of the review. The paradigms and perspectives were provided in the introduction to assure the broad readership had a minimum shared understanding to bring to the review results.
Peer Reviewer #1	Methods	In the search strategy (p. 19) why did you only look for studies that had both disabled and non-disabled populations enrolled?	We looked for studies with both populations as examples of studies that used general population outcome measures and how the study accounted for potential mediating or moderating effects of the presence of disability.
Peer Reviewer #2	Methods	I thought that the methods were clearly articulated including a clear rationale with one exception. Although the inclusion/exclusion criteria potentially explain how the authors winnowed down the literature search results based on the title and abstract, it is not clear how the results were further reduced to the articles that were actually examined in the report. Was the entire winnowing process based on the stated inclusion/exclusion criteria?	Yes, the literature was screened by independent reviewers using the inclusion/exclusion criteria.
Peer Reviewer #3	Methods	it would be helpful to know how "significant collaborative effort" was assessed and defined as an inclusion criteria.	We have added "A publication was deemed to have shown significant collaborative effort if it used replicable methods and multidisciplinary investigators to search for and critically appraise outcome measures, and the results were intended to help establish professional consensus, often through partnership with professional organizations."
Peer Reviewer #3	Methods	typo: "we hand search reference lists . . ."	Typo was corrected.
Peer Reviewer #4	Methods	Clear description of the review criteria used to identify measures and studies of relevance.	Thank you for the comment.
Peer Reviewer #5	Methods	It would seem that the inclusion/exclusion criteria are more than justifiable given the potential scope of the task and given that this appears to be a first step in what is hopefully a course of research that will yield robust health measures for people with disabilities. The criteria seem appropriate and I am not in a position to judge the statistical methodology since I am not a statistician.	Thank you for the comment.

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Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #7	Methods	Inclusion and exclusion criteria are justified.	Thank you for the comment.
Public Comment #2 AOTA	Methods	AOTA questions why the search strategy did not include CINAHL database. Much of the allied health literature related to rehabilitation can be found in CINAHL. Therefore, we are concerned about the possibility that some informative studies were excluded from this report.	In our experience, use of CINAHL for disability/functional limitations/complex interventions has not yielded additional includable studies to datasets already drawing from Medline, PsychInfo, ERIC, and other targeted databases such as Pedro. CINAHL has also been resource costly due to the practice of indexing articles that review single studies published in different journals. Given the already extensive search and screening processes, we determined it was not a cost effective source.
Public Comment #3 APTA	Methods	APTA recommends the inclusion of CIRRIE as a search database (in addition to Pubmed, ERIC, etc). As CIRRIE is NIDRR funded it may have information on additional citations for the key questions.	We have added CIRRIE as a database. We did not find additional citations for the review.
Peer Reviewer #1	Results	The results section is clearly written and the tables were nicely presented.	Thank you for the comment.
Peer Reviewer #1	Results	It was unbelievable that no studies were found to answer KQ1c. Of all the articles reviewed, some must have been directed to process measures. Perhaps the way the question for KQ1c was written and defined was the problem. The question could be rewritten to say "what are the key process measures identified for service access." If you are going to look at process measures, they need to be considered more broadly or you could simply exclude this question.	We addressed this in the limitations of the review.
Peer Reviewer #1	Results	On Table 13, I am not sure what the row for "qualitative" measures and "guidelines" means. Qualitative is a method and not a type of measures. If a paper focuses only on guidelines, these probably should be omitted since it is not a research study.	We have amended the table to say "qualitative feedback." The measure was an open-ended qualitative response item for feedback from providers whose patients participated. Detailed information was provided in the appendix.
Peer Reviewer #1	Results	Table 14 is useful but deserves more discussion and explanation as to how it was developed and how it can be used.	A detailed discussion of The National Core Indicators, as the report states, is beyond the scope of the review. We provided a website source for interested readers.
Peer Reviewer #2	Results	The results were clear and concise.	Thank you for the comment.

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Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Results	Table ES-2/Table 4: The study domain of depression raises questions given the stated exclusion of serious mental illness. Or, is this depression as a co-morbidity to other disabilities?	Depression symptoms in this table is an outcome. We have retitled the domain for clarity.
Peer Reviewer #3	Results	The inclusion of the complete list of National Core Indicators domains and items at the end of the report feels a bit disconnected. It is not clear why this one set of tools was appended here, since the relationship to the key questions or literature search is not obvious, or why this is deemed an "important" effort.	We have revised the NCI paragraph for flow. The NCI represents a significant effort to create a core set of indicators states can use to monitor quality performance.
Peer Reviewer #4	Results	Tables are concise and form an excellent reference.	Thank you for the comment.
Peer Reviewer #4	Results	Table 4- possibly list the 9 ICF domain chapters in a footnote. This is a valuable summary of measures by domain. Improve access to reader by (if possible) including citation number so the measure can easily be retrieved from the list of references. This suggestion goes for many of the tables. It is a shame that you do not have room to describe relevant population for measurement as this would be incredibly valuable.	The 9 chapters were noted. Citations numbers were provided.
Peer Reviewer #4	Results	Critically Evaluated Outcome Measures Practical useful information.	Thank you for the comment.
Peer Reviewer #4	Results	Table 6- excellent useful information summarizing measures and important qualities of them.	Thank you for the comment.
Peer Reviewer #4	Results	Table 7- Balance and falls are not really activities nor is upper limb- you might add for upper limb- "Activities involving the upper limb" and for balance "activities involving balance" and delete falls as it is a consequence.	The table was reproduced as originally published.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #4	Results	KQ1b. Modifiers or case-mix adjusters. Your statement that you did not find any eligible studies of basic medical needs and secondary conditions that examined a mixed population of disabled and non-disabled participants. Our work on staging is tangentially related. We addressed associations between the presence of chronic medical needs (chronic diagnoses) and perceived lack of accessibility features in the home according to ADL and IADL stage in a mixed population of disabled and non-disabled elderly people living in the community. The ICF-based stages define 5 strata for ADL and IADL (measuring the self care and domestic life chapters). Stage 0 includes people without disabilities and stages I, II, III and IV represent increasing disability. Stineman MG, Xie D, Pan Q, Kurichi JE, Saliba D, Streim, J: Activity of daily living staging, chronic health conditions and perceived lack of home accessibility features among elderly people living in the community. J Am Geriatr Soc,59:454-462, 2011. Stineman MG, Henry-Sánchez JT, Kurichi JE, Pan Q, Xie D, Saliba D, Zhang Z, Streim JE: Staging activity limitation and participation restriction in elderly community-dwelling persons according to difficulties in self-care and domestic life functioning. Am J Phys Med Rehabil. 2011;In Press	Thank you for the references. The study was added to KQ1b.
Peer Reviewer #4	Results	KQ1c. Value would be enhanced by providing reference to individual studies in body of paper if possible.	As noted above, references were included in tables.
Peer Reviewer #4	Results	Process measures Table 14- National core indicators- is very useful as presented. Please check "Health" The inclusion of "Have poor health" seems to be of a different dimension from the others in that list that all relate to care processes, although strangely the domain is labeled health.	The table is accurate as produced.
Peer Reviewer #5	Results	I thought that the results section was clear and pointedly communicated the dearth of measures that exist or that could be applied to health outcomes for people with disability. I'm not familiar with the breadth of literature so don't feel prepared to comment on how extensive the search was. All I can say is that these results prompted me to think about ways of helping states moving to managed care to think beyond the standard generic health measures.	Thank you for the comment.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #6	Results	While only 13 articles were reviewed to address KQ1a (What general population outcomes have been validated on and/or adjusted to accommodate disabled populations?), these articles did produce an excellent list of outcome measures used in disability research which are not impairment group specific. Criteria for evaluating the outcome measures and minimal detail about the measures in the list are provided in tables 5-10, but a qualitative critique of the disability and rehabilitation outcome measurement field was not offered. Discussion of consensus building processes to narrow the field of outcome measures were discussed with particular emphasis on the ICF core datasets for specific impairment groups, but the primary limitation of the ICF core dataset approach (that actual validated outcome measures are not provided, simply the most frequently used and important taxonomy codes within the ICF for each impairment group) was not mentioned. Furthermore, the common data elements approach to increasing the consistency of outcome measures by multiple federal agencies (NIH, NIDRR, DOD, VA, and CDC) was not mentioned. Without a comprehensive synthesis of quantitative and qualitative findings of the reviewed articles that integrates the state of the science in outcome measurement for people with disabilities, the implications for further research were quite limited.	<p>The common data elements approach used by the federal agencies, for example the NIH's NINDS, is aimed at interventional studies. While such studies may lead eventually to quality improvement, we did not include them here as they were not aimed at quality improvement nor necessarily aimed at the disabled population. The NCI was included as an example of a standardized set aimed at measuring state performance for state services for disabled populations. Determining where to draw scope boundaries for the review, which examines a field without clear boundaries, will inevitably leave some readers feeling important subjects were not examined.</p> <p>We revised the ICF core set section to note that the effort is on-going and testing and validation is planned, and that similar standardization efforts are on-going in other areas of research.</p>
Peer Reviewer #6	Results	A total of 43 articles addressing KQ2 and 3 were reviewed. Tables were provided indicating the number of articles by target group and age category and the number of measures by age category for care coordination among providers or between provider and family members or social services. Minimal detail was provided about the articles and measures in appendices B1 and 2, but no qualitative synthesis of the findings were provided. The body of the report included mention of the NCI and a table of NCI quality indicators listing the items by domains, but no mention was made of NCI in the executive summary, which seems an oversight.	We have added a brief discussion of the NCI to the executive summary.
Peer Reviewer #7	Results	I believe that the general finding that "the scarcity of literature indicates the early stages of research development in this area" is generally accurate. But really, anyone in the field of disability already knew that.	Thank you for the comment.
Peer Reviewer #1	Discussion	I think the discussion of the results is inadequate. The paper has provided a lot of information but it is not clear how it can be used. There needs to be a more thorough discussion of what the results mean.	The discussion section has been revised.

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Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #1	Discussion	The research issues and gaps are logical but they are not clearly developed into specific recommendations. I would like to see specific recommendations developed for target groups: researchers, policy makers, funding agencies, and others.	We have expanded our discussion of research recommendations. We understand, given the broad scope of the review, that not all readers will likely be satisfied with the level of specificity.
Peer Reviewer #1	Discussion	The criteria presented in Table 15 could have been used to discuss the studies reviewed in the paper. Just telling the reader to use these criteria in the future is not very helpful.	Table 15 was a reproduction of criteria used in several of the critical appraisals reported in the results. We believe it will be useful example to some readers who may be considering their own efforts in evaluating outcomes.
Peer Reviewer #2	Discussion	The implications of major findings are clearly stated and the future research directions are also clear.	Thank you for the comment.
Peer Reviewer #3	Discussion	The authors note that the results indicate the “early stages of research development”; alternatively they could also indicate systemic bias against consideration of disability as a comorbidity worth researching. Also, since “The major limitation of this work is the lack of sensitivity and specificity of the search algorithms.” It may be premature to draw any conclusions from this self-described “sample.”	We have included the alternative hypothesis in the discussion section as part of the general discussion of the research bias experienced by people with disabilities. However, from our experience in the systematic review field, when literature is as difficult to locate as we experienced with this review, it generally indicates lack of research development. This can include the idea that a systematic bias, once realized, will be addressed, and that such systematic biases are more likely to be undiscovered and unaddressed during earlier stages of research development.
Peer Reviewer #3	Discussion	The conclusion also states “The broad scope of the review was, however, a useful endeavor because its findings underscored the need for coordination and collaboration among the three overarching approaches to studying outcomes—medical, rehabilitative, and supportive services.” The introduction already asserts a priori that these three disability paradigms are not sufficiently integrated. While almost undoubtably true, it is not clear that the results add any further evidence to this claim.	We disagree. We believe the lack of search results can be taken as evidence of lack of coordination and collaboration. This contributes to moving the idea from assumption to evidence-based.
Peer Reviewer #3	Discussion	Would recommend tightening or reformatting the “research issues and gaps” section to make the suggested areas of future research, database development, etc. more obvious.	The section has been revised.

Commentator & Affiliation	Section	Comment	Response
Peer Reviewer #3	Discussion	Again I have concerns about the concept of disability as a comorbidity. I would be more comfortable considering disability as separate a domain distinct from diagnoses but related to diagnostic comorbidities. The assumption that it is important to consider disability in case mix is the key point.	As noted above, the language has been revised.
Peer Reviewer #4	Discussion	The first paragraph does a fine job framing usefulness of the study to research.	Thank you for the comment.
Peer Reviewer #4	Discussion	Table 15- would add impairments or population(s) for which relevant, and level of measurement (person versus population level). A small but important point of clarity- for the statement- "A geriatrician might use a simple ADL that taps six domains, including dressing. Dressing is an activity or task by ICF rather than a domain (which would generally include multiple related activities. The multiple ADLs generally are considered to represent a domain of activities. In general the example provided here of how the same set of tasks might be visualized differently by a geriatrician and occupational therapist is excellent.	Table 15 was a reproduction of criteria used in several of the critical appraisals reported in the results. We have added the suggestions to the text.
Peer Reviewer #4	Discussion	"We found very few direct examples of work conducted from the perspective of disability as comorbidity." This seems to be a central conclusion of your work. My interpretation is that you are using the term comorbidity to express that disability should be among the covariates as a co-morbid circumstance along with the chronic illnesses people have. Secondly, disability should be considered among essential case mix factors when looking at populations. At a minimum please define comorbidity as representing a broader concept than is typically used in medicine as representing collections of chronic diagnostic conditions.	As noted above, the comorbidity language has been modified. The discussion section has also been revised.
Peer Reviewer #4	Discussion	Distinction between granular and summary or generic measures is key, as is the concept of mapping overlap.	Thank you for the comment.
Peer Reviewer #4	Discussion	Research Silos- Can you offer ideas on how to break these down?	We have included specific ideas for researchers, federal agencies, and professional organizations, in the discussion section.
Peer Reviewer #4	Discussion	Limitations: Appropriately acknowledged	Thank you for the comment.
Peer Reviewer #4	Discussion	The final statement, "Collaboration and coordination of measurement efforts across medical interventions, rehabilitation and social support provision is needed." Is fundamental and forward looking! It is at the essence of need. All sectors of the health care system must work together.	Thank you for the comment.

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Peer Reviewer #5	Discussion	I think that the implications are fairly obvious – I do think a more explicit description of next steps and potential approaches would be very useful.	We have revised and expanded the discussion section.
Peer Reviewer #7	Discussion	I don't think any really important literature was omitted. There is not a clear path from the results to future research that is presented. It would be helpful if there was.	We have revised and expanded the discussion section.
Public Comments #1 AAPM&R	Discussion	The AAPM&R largely endorses this recommendation [Disability and quality improvement research could benefit from organized databases of critically assessed outcome measures], as current databases lack classification of the severity of illness, diagnosis and disability. In order to account for condition variability, severity measures are a key element that should enjoy parity with other components indicated. Without this information, practices outside of a rehabilitation setting would have to manually collect this data which could allow for the non-standardization of this metric. We concur that “much could be gained from developing a core set of outcome measures” for persons with disabilities.	Thank you for the comment.
Public Comments #1 AAPM&R	Discussion	The report concludes that by considering disabilities as a co-morbidity, it follows that focus would transfer to generic outcome measures. However, measures that include disability as a co-morbidity may not capture data regarding the complexity of the condition. Instead, by treating disability as a mediator, and allowing for the incorporation of complex variables that disability encompasses, it would allow inclusion of the complexity of a condition and still allow use of generic outcome measures that could be compared across diagnoses.	We have modified the language for comorbidities.
Public Comments #1 AAPM&R	Discussion	The Academy supports findings that, drawing from existing resources such as the International Classification of Functioning, Disability and Health (ICF), can be helpful in embracing a holistic view of disability by combining body, individual and societal perspectives to come to a common metric. However, the references to pain and fatigue in the ICF do not incorporate the complexity of their relationship to health and function. Because pain and fatigue are common contributions to disability, the Academy believes they require social dialogue to understand their impact on the measurement of outcomes for people with disabilities. This may be beyond the scope of this study, but the Academy believes it should acknowledge the need for expanded analysis.	That level of discussion of the ICF is beyond the scope of the review, as the reviewer acknowledges. However, we did note in the discussion section that the ICF is not sufficient to address all individual or system level outcomes relevant to the levels of analysis addressed by this review.
Public Comments #1 AAPM&R	Discussion	Similarly, even though this report excludes pediatric and mental health, the AAPM&R believes there is a need for analysis of these populations when designing common metrics.	The review did include pediatric populations.

Source: <http://effectivehealthcare.ahrq.gov/search-for-guides-reviews-and-reports/?pageaction=displayproduct&productID=1280>

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Commentator & Affiliation	Section	Comment	Response
Public Comments #1 AAPM&R	Discussion	Although a few studies were listed that focused on patient reported outcomes (PROs), the use of sophisticated computer adapted testing methods such as Am-PAC or PROMIS, designed with ICF concepts and a function measure, is not mentioned. PM&R, as a patient-centric care specialty, would like to emphasize the importance of PROs because of the ability of these studies to be used longitudinally. The capability to measure and study outcomes over time with precision would mitigate the ceiling and floor effect of other measures, specifically when studying pain, quality of life, or function.	The use of data collection tools being used in PROMIS, was mentioned in the discussion of universal design in the introduction section. We did add further language clarifying the use of computer adapted testing as one of those tools. We also added a brief paragraph to the discussion section regarding the use of patient reported outcomes.